movement, wrote, "As long ago as the late 18th and 19th centuries, mutual aid organizations served not only to deal with the imminent needs of their members, but served also to politicize them." Or, as we might say today, to raise their consciousness.

Let me briefly articulate some of these political functions that have always been present. When I speak of politicization, I also mean a recognition of the power dimension in self-help. This was brought home to me when I was reading Katz's and Bender's book, but it also was emphasized for me by the responses to the survey that was sent out to the participants in this workshop. Many of the respondents said that a crucial issue to be faced in the provider-patient relationship is who has control and who is making the decisions. What this reveals to me is a strong concern about imbalance of power.

To regain this balance, almost all self-help groups in the health care area have engaged, either implicitly or explicitly, in what might be called a process of demystification—of a particular problem, disease, or disability, of the nature of treatment, and of what care providers can give. What some in the self-help movement call empowerment also has political dimensions. For many mutual support groups, empowerment takes the form of personal advocacy in helping an individual get through the system, whatever that system may be.

For other groups, empowerment goes beyond that and becomes what I would call interactional advocacy, which is based a realization that in dealing with the health care system one should not go it alone because the power imbalance is too great. I got that particular insight from a group called the Black Panthers, who were setting up a group in my home town

of Dorchester around 20 years ago. The Panthers felt that no person, especially if poor, old, and black, should go alone into a situation where there was such an imbalance, so they always sent someone to accompany anyone needing access to the health care system.

A third political aspect of empowerment occurs in groups that are not organized around a single specific category of disease or disability but cut across a number of them. The perspective of these groups is that certain kinds of actions can be accomplished far better if the similarities among members, irrespective of the particular nature of their individual conditions, is recognized. There may also be an unwitting recognition in such groups that specialization according to disease or disability categories can produce fragmentation and insularity, and an attitude of, "my disease is worse than yours."

For some people even this cross-cutting approach is not adequate, however, and one result has been the creation of alternatives to the mainstream health care system itself, all based on the concepts of self-help. In the late 1960's I was part of a group that created one of the first ostomy rehabilitation clinics in the country. Though based in a hospital and headed by a physician, it was run completely by people who had ostomies. Things got even more explicit in the late 1960's and 1970's. Women formed their own self-help clinics when they felt that the predominant health care system could not hear their voices. A number of disability groups followed suit and eventually created not only a movement of the disabled but independent living centers for the disabled.

Yet, for at least these two segments of the self-help movement, these internal gains were still not sufficient. They per-

ceived a need to work for change in the political, legislative, and social arenas. This idea was perhaps first articulated in the book, Our Bodies, Ourselves, which came from a group of women engaged in self-help. The thesis of these groups within the women's movement was that it is not enough just to support ourselves, we also have to understand the system that is oppressing us so we can work for changes. Out of this movement arose groups like the Women's Health Network and the National Black Women's Health Project.

The development of the disability rights movement was quite similar. First there were various groups organized along specific disability categories— cerebral palsy, blindness, spinal cord injury, and many other conditions—and quite separated from each other. The 1970's, however, saw the spawning of much broader and more action-oriented organizations such as Disabled in Action and the American Association of Citizens with Disabilities.

I want to discuss a phenomenon occurring in our colleges and universities because it illustrates the fruits of empowerment and proves that even academics can learn. There was a paper in the workshop packet that everyone here received saying, " . . . it is not too far-fetched to predict that mutual support psychology will become a staple in graduate school curricula, just as therapy-related courses are today." Well, that day has already come; such courses exist. Also, in the footsteps of self-help actions of the civil rights movement that led to black studies on campuses, and similar actions in the women's movement that led to women's studies, there is now a movement on campuses to create disability studies. The last time I counted, there were around 40 campuses across the country that had started disability studies, and there are now three academic journals for disability studies, as well as a newly scholarly organization called the Society for Disability Studies whose members include social scientists, many with disabilities.

Let me end with a warning. I think it is in the nature of this historical moment that the encounter between health care providers and patients or people with disability in their families may have the elements of confrontation. In previous times, when patients felt disregarded, abandoned, or misunderstood, they always had a recourse but it was a passive one: noncompliance. That is changing, and words that were once used only for rhetorical effect, like negotiation, have become real if not legal parts of some practitioner-patient relationships. People with disabilities, people in the self-help movement, have begun to find their voices, and occasionally those voices may be harsh and strident. If so, it is because the time has been so long in coming, and there is often the feeling that we have to shout to be heard.

J. Katz, a professor of psychiatry and law, has written that the reluctance of health care workers to share information and converse meaningfully with their patients or their families has a 2,000-year history. This surely means that the changes to come will not come overnight, but it does not mean that providers and self-helpers can passively wait for them to happen. For if we do, we will find ourselves living out a 1960's cliche: if we are not part of the solution, we are certainly part of the problem.

DELIBERATIONS OF THE WORKSHOP

Overview of the Workshop Process

The Surgeon General's Workshop on Self-Help and Public Health had a number of unique features. It was designed to be highly participatory, with all participants having equal standing, and it was highly task oriented. The goal of the steering and planning committees was to create an open process in which all ideas merited equal consideration in an environment that permitted scholars, human service professionals, and self-help leaders to share their expertise. The deliberative process of the workshop itself embodied the ethos of self-help since it was structured to give theoretical knowledge and experiential knowledge equal value.

The Modified Delphi Technique

The specific process used in the workshop was a modification of the Delphi technique, a method originally developed in defense-oriented "think tanks" to gather the best thinking of experts on a topic in a short amount of time. In the original Delphi model, experts were asked to respond to specific questions and rank their responses according to priority. However, there was no personal interaction among the experts in the original Delphi technique; they worked independently of each other and submitted their responses in writing. In contrast, the modified Delphi technique used in the Surgeon General's Workshop involved direct interaction of participants deliber- ating in small groups. Thus the workshop used some parts of the original process but combined them with humanistic approaches, particularly those used by self-help groups.

The Delphi process, both in its original form and in this modification, encourages the ranking of ideas to increase the probability that the best ideas will come out on top. Although the process can produce some tension, that tension was regarded by the workshop planners as an essential part of the creative process and capable of bringing forth the best ideas.

Small-Group Deliberations

Workshop participants were assigned to one of eight groups, each of which reflected as much as possible the composition of the entire workshop. These working groups spent the better part of a morning session examining specific areas of the potential partnership of the self-help movement and the health care delivery system and proposing recommendations. Each group was led by a specially trained facilitator responsible for helping organize the work, guiding the group, maintaining a schedule, and managing conflicts. The facilitator was assisted by a recorder who was responsible for keeping a record of the group's deliberations and proposed recommendations.

Each of the eight small-group workshops began with a brainstorming session,

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a process whose general guidelines are as
follows:

- The sky's the limit, so don't censor
  your ideas—express them.
- Build on the ideas of others.
- Don't judge or criticize other people's
  ideas during brainstorming.
- Hold off any discussion until the brain-
  storming session is over.

The brainstorming session was fol-
lowed by discussion to refine, expand, or
consolidate the ideas that had been pro-
duced.

This process, which occurred in each
of the eight working groups, yielded 40
recommendations, 5 from each group.
These were presented to the full work-
shop, which considered and debated them
all. After modifying and consolidating
several of the recommendations through
normal parliamentary procedures and
selecting the 16 most favored, the selected
recommendations were divided among the
small-group workshops for development
of possible implementation strategies.

CHAPTER IV

RECOMMENDATIONS TO
THE SURGEON GENERAL

The 16 recommendations of the workshop are listed here in the order in which they were addressed by the Surgeon General in his response (see Chapter V). This ordering does not reflect the relative priorities of the recommendations as suggested by the number of votes each one received. The number in parentheses after each recommendation indicates that recommendation's level of approval by the participants. Recommendations that received the most votes have the lowest numbers. Suggested strategies for implementing these recommendations are in Appendix B.

Recommendation No. 1: Develop, fund, and support a proactive national centralized information center for referral to existing self-help groups and clearinghouses and for assistance in the formation of new groups (Priority: 5). Many self-help groups are small, single-chapter organizations without resources to advertise their services to those who need them. Workshop participants favored creation of a nationwide service to match people with appropriate existing self-help groups, identify areas and conditions where new groups are needed, and support the establishment of new groups.

Recommendation No. 2: Increase the effectiveness of self-help groups by facilitating communication among groups and disseminating successful models for self-help (Priority: 16). There are many variations among groups in application of

the self-help concept, and there is no one best model that is appropriate for all groups. Self-help groups typically examine what is being done elsewhere and select the approaches that seem right for them. The workshop participants saw a need to improve this process by more systematic dissemination of information among groups.

Recommendation No. 3: Incorporate self-help concepts into the policy and practice of governmental and nongovernmental organizations, including health care providers (Priority: 4). This recommendation expresses the workshop participants' conviction that the self-help process is adaptable to a wide range of situations and can be incorporated successfully in many existing programs. The participants felt that this incorporation could bring the benefits of self-help to those being served by existing programs without creating a totally new service delivery system.

Recommendation No. 4: Establish a structure within the Public Health Service for the promotion and development of self-help (Priority: 8). This recommendation expresses the conviction of the workshop participants that a partnership between self-help and public health is both desirable and feasible. It also recognizes that the self-help movement, to realize its full potential as an instrument for protecting and improving public health, needs formal recognition, promotion, and

support within the preeminent Federal public health agency.

Recommendation No. 5: Develop multimedia campaigns aimed at the public, human services professionals, and self-helpers (Priority: 15). Members of self-help groups at this time tend to identify themselves in terms of a specific problem that brings them together, for example, as cancer patients or alcoholics. One result is that the term self-help is used in many different ways both by human services professionals and the general public. Workshop participants advocated an educational effort to explain what self-help is in the broader sense, what it can and cannot do, and how people can find or form a group appropriate to their needs.

Recommendation No. 6: Support collaborative research and demonstration projects using methodologies appropriate to self-help group approaches and values (Priority: 3). Systematic study of the self-help process is still very limited, especially study of the mechanisms responsible for success. Research in this area has been hindered by the limits of current research methods in studying highly informal associations dedicated to providing full support to all their members. The workshop participants recognized the importance of research on self-help but stressed the need to develop appropriate methodologies.

Recommendation No. 7: Develop mechanisms for linking self-help resources and the formal services delivery system as equal partners, giving special consideration to programs for special populations (Priority: 7). The workshop participants endorsed the idea of a partnership between self-help and public health and urged the creation of appropriate mechanisms to facilitate it. They urged

the creation of mechanisms that recognize both equality in the partnership and appreciation of the unique contributions that self-help groups and formal service organizations can each make to public health.

Recommendation No. 8: Develop, promote, and incorporate mechanisms to educate primary and secondary school children about self-help through education and health care delivery (Priority: 14). Workshop participants believed that self-help concepts are beneficial for people of all ages, including school children. Children, no less than adults, can feel isolated by their problems and can benefit from mutual caring and sharing.

Recommendation No. 9: Establish, coordinate, and strengthen self-help clearinghouses and other networking resources at national, State, and local levels, with self-helpers having equal involvement in governance and implementation (Priority: 13). The workshop participants recognized that self-help clearinghouses are playing a major role in linking the public with groups, creating networks among groups, and educating professionals and the public about self-help. The participants urged support for the further development of these critically important resources.

Recommendation No. 10: Establish a national center or institute to fund, coordinate, and facilitate research, training, and dissemination of information on self-help (Priority: 6). This recommendation, like Recommendation No. 1, addresses the current fragmentation of the self-help movement. The workshop participants urged better communication among self-help groups as well as training for leadership in self-help and expansion of knowledge about self-help for the public, the professions, and self-helpers themselves.

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Recommendation No. 11: Channel resources for self-help into underserved areas and populations such as minorities, rural areas, low-income people, the aged, people with disabilities, alternative family groupings, the homeless, and youth (Priority: 10). Although there is much evidence that the self-help concept is adaptable to serving minorities, low-income, and other special populations, most self-helpers at this time are white, middle-class, and female. The workshop participants saw a clear need to reach underserved populations, who stand to gain much from self-help.

Recommendation No. 12: Develop and advocate national policies that recognize the validity and role of self-help groups in the full age spectrum of American society (Priority: 12). The workshop participants felt that the validity of self-help concepts should be reflected in public policy, particularly in the design and implementation of public health programs. A continuing focus on self-help within the U.S. Public Health Service, with participation of self-help representatives in shaping relevant policies and objectives, was considered essential.

Recommendation No. 13: *Increase minority leadership in the self-help movement and enhance the sensitivity of self-help organizers and groups to culturally diverse populations (Priority: 9).* This recommendation, like Recommendation No. 11, recognizes the benefits that self-help can provide for minorities, who are currently underserved. The workshop participants considered the development of self-help leadership within minority populations essential and entirely consistent with the central idea that self-help groups should arise from indigenous needs and should be self governing.

Recommendation No. 14: *Incorporate information and experiential knowledge about self-help in the training and practices of professionals (Priority: 1).* The participants felt that exposure to the concepts and benefits of self-help should be included in the training curriculums of all helping professions. Including this knowledge in the training of health professionals was considered especially important for developing a partnership between self-help and public health.

Recommendation No. 15: *Develop and influence public policy through networking, coalition-building, and advocacy (Priority: 11).* This recommendation, which was mainly directed to the self-help movement itself, reflects a major theme that emerged at the workshop—that self-help groups need to end their isolation and fragmentation and begin working together to achieve common goals. It was evident to many participants that, although self-help groups represent a large constituency, too few of them have worked together to influence public policy on issues that affect their membership and the self-help movement as a whole.

Recommendation No. 16: *Increase Federal, State, local, and private funding for self-help groups and activities (Priority: 2).* Typically, self-help groups are very small, very informal, and unskilled at "grantsmanship" and other kinds of fundraising. Yet collectively they are providing indispensable services that improve health and the quality of life for millions of people in a highly cost-effective manner. The workshop participants believed that with adequate financial assistance the self-help movement could spread its benefits to many more millions of people. They therefore urged increased funding of self-help activities from all levels of government as well as from the private sector.

THE SURGEON GENERAL'S RESPONSE

C. Everett Koop, M.D.
Surgeon General
U.S. Public Health Service

When I became a pediatric surgeon in 1946 there were only five others in the entire country, so many of the procedures I did had never been done before. This new medical specialty allowed many youngsters to survive what were previously considered hopeless diagnoses and be habilitated into our society.

I'm talking about problems such as establishing continence in a 10-year-old child born without a rectum.

I'm talking about spina bifida, which in those days was rarely operated on, and about hydrocephalus, for which there was no cure or prevention.

I'm talking about youngsters born with no esophagus or with an esophageal defect that required years of training in swallowing to prevent choking and asphyxiation.

One way I helped families who had to cope with problems like those was by introducing them to each other. It was for self-help and mutual aid, only I didn't call it that. I was reinventing the wheel and didn't know it.

As time went on, I began to attract a number of children with tumors. I must tell you that this was an era when pediatricians practically denied the existence of cancer in children. It was an era when even the word "cancer" was unspeakable. I remember actually being forbidden to use it when I was on a radio program talking about pediatric surgery.

One of the frequent consequences of childhood cancer was death on the hospital ward, and I saw that after such a heartbreaking event the student nurse would lean on the staff nurse, and the staff nurse would lean on the supervising nurse. Eventually there was no one to lean on but me. So we started a self-help group, though we didn't call it that, for grieving pediatric care providers. We met regularly but also spontaneously when the pain became overwhelming. To this day in the hospital where I worked there is still a group that meets with the chaplain to talk out their feelings.

I put in the first shunt for hydrocephalus, to drain the excessive cerebrospinal fluid out of the brain ventricles into the peritoneal cavity. When word of this successful surgery spread, children with untreated hydrocephalus came from far and wide. There were days when I would arrive at work to find a trailer parked in the hospital courtyard, and in it would be a family with a hydrocephalic child. The heads of some of those children were huge, as large as the biggest pumpkin you've ever seen. Many of them had heads of such size and weight that they could not be conveniently moved even in a wheelchair. Many of these children were intelligent, but at that late stage the shunt operation couldn't be done. The frustrated families of these youngsters became the focus of another self-help group.

A pediatric surgeon learns early that there are different types of grieving parents. Those who lose their child in an accident have their own kind of grief. Those

whose children die in mid-childhood of chronic diseases like cancer have a special kind of grief, because they lose their children after they have become people, after they have developed personalities. There is special pain in knowing that the future of that child, that small person, will not be permitted to unfold. Some of these parents seem to lose their children twice—first when the hopeless diagnosis is made, and again when the child dies. The real death is sometimes easier to bear, because it brings a sense of release and relief. But sometimes the period between diagnosis and death is long and extraordinarily difficult.

The grief of parents who lose a child after a prolonged illness during the neonatal period is also of a special kind, because it is often compounded by a feeling of unreality. Their child had to be taken from them for intensive care before they could even adjust to the fact that they were parents. They never even had a chance to bond to the child.

So, about 40 years ago I began to bring grieving parents together. I do not mean to imply that excellent groups such as the Compassionate Friends are offshoots of what I began. I only offer my experience to illustrate the fact that a great need will evoke the same kind of response in many places at the same time. I tell you these things to let you know that even 40 years ago I was interested in and concerned about self-help. I tried to address the same problems everyone here is concerned about—isolation, powerlessness, alienation, and the awful feeling that nobody understands.

Before I respond to your recommendations let me say that, although the leadership in previous Surgeon General's workshops has been excellent, none of the other workshops has matched the superb organization of this one. I am most grateful. I have come to admire, respect, and feel affection for several individuals I have met here during the past few days. I wish I could have gotten to know all of you and heard your personal histories. I thank all of you for being who you are and doing what you do, and I am grateful for the thoughtful and excellent work you have done here at this conference.

Turning now to your recommendations, I think **Recommendation 1**, *establish a national self-help information center*, is right on target. Let me give you an analogy to explain why I think so. I'm sure you all remember the Baby Doe case and the fact that I was the lightning rod in the Administration for that particular issue. It was appropriate for me to be the lightning rod, because when I came to Washington I had probably operated on more Baby Does than anyone else in this hemisphere.

I was convinced that Baby Does existed for two reasons. The first reason was obstetricians or pediatricians making snap judgments in the delivery room about lesions they did not understand and about habilitation processes they had never witnessed. The second reason, and the more important one, was that pediatricians did not know as much as they should about the support systems that existed in the community to help patients and their families go through the difficult times that accompany certain diagnoses.

I knew those things and acted on that knowledge, and now, in various parts of the country, there are computerized data retrieval services available to parents and physicians alike. They can get information tailored to their own understanding and needs. I see no reason why this cannot be done for self-help, and I will investigate how it might be done and report back to you in some fashion.

Recommendation 2—*increase the effectiveness of self-help groups by facilitating communication among them,*

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with funding, technical assistance, and dissemination of successful self-help models—is also appropriate. That communication has to be facilitated, and I think some of your other recommendations refer to specific ways that might accomplish it. All these things need funding and technical assistance, and I will investigate how that might be best accomplished. However, I think the dissemination of successful models is up to you, and I will look forward to a Surgeon General's conference as a followup to this one, perhaps 3 years from now, when a planning committee will bring model programs together at a national meeting so people can examine, appreciate, and attempt to replicate them in their own communities.

I think the merits of **Recommendation 3**—*build self-help into public health policy and into the policy and practice of governmental and nongovernmental organizations, including health care providers*—are self-evident. If we are to do anything with any of the other recommendations, self-help must be transformed into policy. I pledge to do all I can to build self-help into public health policy. I can do that best at the governmental level, but the Surgeon General is not without influence in other sectors.

Recommendation 4—*establish a structure within the Public Health Service for promoting and developing self-help*—ties all of the previous recommendations together. I believe such a structure should be established, and I will explore ways to accomplish it. I will present your recommendation to Dr. David Sundwall, Director of the Health Resources and Services Administration. Dr. Sundwall has a sincere interest in self-help, and I will ask him to consider the possibility of establishing such a structure within his agency. I will also speak to Dr. Michael McGinnis, who directs the Office of

Health Promotion and Disease Prevention, to see if some aspects of this recommendation could be carried out by his agency, whose efforts reach far into the community. I will not stop there, however, because self-help cuts across every health-related service provided by government. Almost every cabinet department has some health component, and I will explore the possibilities of creating a focal point for self-help activities with all of them, taking care to avoid overlap and duplication of effort.

The aims of **Recommendation 5**—*sponsor an informational campaign aimed at the general public, human service professionals, and self-helpers*—I think can best be accomplished by producing a book, and I would support that in any way I can. I think it should be produced by a commercial publisher and not be a government publication. I think any commercial publisher who knew that there are 500,000 self-help groups in this country would recognize that such a book would be a best seller. I would like to work with representatives of this group to see how this might be accomplished. One possibility is a multiauthored book with the Surgeon General as editor, which would give the prestige of that office to the endeavor. I am 75 percent certain this could be accomplished. My 25 percent uncertainty comes from awareness of the difficulties a Surgeon General might have in accomplishing this without appearing to endorse specific programs, which is forbidden by the rules of ethics that govern the person holding that office.

Recommendation 6—*support collaborative research and demonstration projects using methodologies appropriate to the self-help approach*—is extremely important. As we all know, the self-help movement, with its estimated 500,000 groups across the country, has had

phenomenal growth and has reached a stage of maturity, so future development should probably be in consolidation and networking. Extension of the self-help initiative in America will require specific information based on research with appropriate methodologies. We realize that self-help groups and scientific investigators may have conflicting purposes and needs, and we will do our best to iron out these difficulties, perhaps in the wording of grant proposal guidelines.

Recommendation 7—*identify mechanisms for linking self-help resources and the formal service delivery system as equal partners, giving special consideration to programs for special populations*—ties in with some of the other recommendations. I think we do need networking, not only at the grassroots level but through self-help clearinghouses. I think creating a partnership between self-help groups and the formal health service delivery system will require a major educational effort, which might culminate in a national conference of self-helpers and health professionals a few years from now. This educational effort is the subject of your next recommendation, number 8.

Recommendation 8—*develop, promote, and incorporate mechanisms to educate primary and secondary school children about self-help through education and health care delivery*. I will encourage the incorporation of knowledge of self-help resources and their value in the education of young physicians, nurses, and other health professionals. They need to know that self-help is an important resource without which their patients will be shortchanged. The Bureau of Health Professions within the Health Resources and Services Administration might be helpful in developing guidelines for this education, and I will bring this recommendation to their attention.

However, regarding the incorporation of self-help education at the primary and secondary school levels, such decisions are made in local communities and States. The Federal Government has no direct role in these decisions. I can promise only to refer your recommendation to the Department of Education for consideration.

Recommendation 9—*establish, coordinate, maintain, and strengthen self-help clearinghouses and other networking resources on national, State, and local levels, involving self-helpers in decisionmaking*—is somewhat covered by your previous recommendations. That self-helpers ought to be involved in decisionmaking goes without saying.

Recommendation 10—*establish a national center or institute to fund, coordinate, and facilitate research, training, and public dissemination of information on self-help and mutual help*—may be premature. I think we first have to convince the professions and the public that we can do what we think we can do, and then the time will come to move in that direction. Let me call your attention to the fact that a national center for nursing research was established only last year, and it took 30 years of effort to do it.

On **Recommendation 11**—*channel resources for self-help into underserved areas and populations such as minorities, rural areas, low-income people, and youth*—I think the Public Health Service can serve you well, because its National Health Service Corps is serving the populations you named in precisely the kinds of areas you named. I will do my part to provide information about self-help to all in the Public Health Service who deal with these areas and populations, including the National Health Service Corps and the Office of Minority Health, and I will direct their attention to any data bases that might develop.

Recommendation 12—*develop and advocate for a national health policy that recognizes the validity and the role of self-help groups and recognizes the full age spectrum of the American society.* I think this is partly answered by the fact that I am here and have given the prestige of my office and the support of the Public Health Service to this meeting. Establishing self-help help in national health policy may be a short or a long way off, but I can assure you that this Surgeon General recognizes the validity and the role of self-help groups, recognizes that they cut across every aspect of health care delivery in the country and across all age groups, and will inform and advocate on self-help for the duration of his term.

Recommendation 13—*increase minority leadership in self-help and enhance the sensitivity of self-help providers to culturally diverse populations*—is consistent with my aims in everything else I attempt to do, whether it is in smoking cessation, AIDS, family violence, or care of aged: to develop leadership in the minority groups, include them in any planning for the future, and enhance the sensitivity of others.

Recommendation 14—*change knowledge, attitudes, and practices of health and human service providers by providing information in formal professional training, through direct personal contact between professionals and self-helpers, and in other ways such as postgraduate training and continuing education, about self-help groups and their benefits; and extend these same principles to other professions who contact people in trouble, such as police, clergy, school counselors, and probation officers.*

This is probably the most far-reaching of your recommendations and certainly the longest, but it covers many of the things I have already promised to address. We have covered the matter of incor-

porating self-help knowledge in the training of health professionals, and I think once that is established, post-graduate studies, on-the-job training, and continuing education will inevitably follow. However, I will bring this recommendation to the attention of people involved in continuing education, and I will do my best to encourage direct personal contact between professionals and self-help groups.

On extending knowledge of self-help to other professions such as law enforcement, it is not always easy for the Surgeon General to step over the boundaries between health and other domains, but it can be done and I am not new to it. My work on violence and sexual abuse of children has crossed the borders between the Department of Health and Human Services and the Department of Justice and has reached down to the level of police and juvenile courts. I will use every opportunity to bring your message to people these other fields.

Recommendation 15—*develop and influence public policy through advocacy, coalition building, and networking*—I think has been covered in everything I have said so far.

Recommendation 16—*increase Federal, State, local, and private funding for self-help groups and activities*—deals with economics. I recognize the need for increased funds, but I must tell you that I have no budgetary authority. However, I do have the power of moral suasion. If that were not so, we would not be meeting here. I will do what I can, but I think increasing the level of funding is based on performance and high visibility over time. I pledge to do everything I can, inside and outside the Federal Government and including the private sector and foundations, to increase funding for self-help groups and their activities.

Those are my responses to your recom-

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mendations. Let me add that I will seek to establish a national toll-free number with TDD voice to provide referral information on self-help groups and State and local self-help clearinghouses. I am also willing to help develop and deliver up to three public service announcements on self-help originating from the Office of the Surgeon General during the next year, and I will be looking for you to be helpful in that. And I will promote an awareness of self-help in all my dealings with professional associations, government agencies, and the private sector.

I want you to report progress to me as it develops, through Heddy Hubbard in the Health Resources and Services Administration, and I will see that you are periodically informed of the progress we have at our end. Through the Office of Intergovernmental Affairs, a part of the Department of Health and Human Services, I will see that everything we have discussed here is made available to the State, territorial, and municipal health officers.

A self-help coordinating committee representing appropriate Public Health Service agencies is also on my agenda, and you yourselves may want to seek a way to become a more formal body to meet and deal that group. In the past, I have been able to help groups such as yours find funds to organize and seek a 504C3 tax exemption. Though I cannot promise a positive result, I will do the best I can in the next budgetary year to find funds for you if you decide you want to become a more formal organization, so you out there can have representation with us in here.

In conclusion, I trust that you understand the extraordinary complexity of the proposals and strategies you have recommended. You know where my heart is in this matter. Though I promise you absolutely nothing about eventual outcomes, because I can't, I pledge my best efforts to achieve the worthy goals you seek.

Thank you all for coming.

CLOSING REMARKS

Mark Mayeda

Dr. Koop's words are a great encouragement to all who are involved in self-help and mutual help. It is important for us to realize, however, that the task ahead is mainly our responsibility and that we ourselves must follow up on the recommendations we have made and not simply look for the Surgeon General to do it all for us.

Something else we all need to remember is that self-help and mutual help are not limited to health issues. It is not just groups of people with particular diseases or disabilities getting together and helping each other. It goes beyond that. It is a many-faceted movement whose central feature is people empowering themselves and each other to deal with all the challenges they encounter throughout their lives.

PRE-WORKSHOP ACTIVITIES

Background Readings Supplied to Participants

Before the workshop, the planning committee's subcommittee on issues development sent participants selected background readings to give them a common knowledge base. The materials dealt with a wide range of issues, some of them controversial, that surfaced during a preworkshop survey of key informants, callers to self-help clearinghouses, and care providers. As a service to interested readers, the materials and their sources are listed here.

Executive Summary: Report to the Steering Committee for the Surgeon General's Workshop on Self-Help and Public Health. This summary of the results of the pre-workshop data collection activities is available from the Self-Help Division of Ambulatory Care and Health Promotion, American Hospital Association, 840 N. Lake Shore Drive, Chicago, IL 60611 ($0.85 and self-addressed 9 x 12 envelope.)

Plain Talk About Mutual Help Groups. Published by the Alcohol, Drug Abuse, and Mental Health Administration, Rockville, MD 20857.

Composite of the Properties of Various Types of Self-Help Organizations. Table A1 from Powell, Thomas J., Self-Help Organizations and Professional Practice. Silver Spring, MD: National Association of Social Workers, 1987, pp. 319-323.

Self-Help Mutual Aid Groups: A Different Helping Paradigm? by Borkman, T. Prepared for the Surgeon General's Workshop on Self-Help and Public Health, July 1987. Single copies available from Thomasina Borkman, Department of Sociology, George Mason University, 4400 University Drive, Fairfax, VA 22030 (stamped, self-addressed envelope).

"Explorations in Self-Help and Mutual Aid." Excerpt from Proceedings of the Self-Help Exploratory Workshop (Borman, L., ed.) held in Chicago June 9-12, 1974. Describes a self-helper's experiences in establishing a committee to combat Huntington's disease. Available from the Self-Help Center, 1600 Dodge Ave., Suite S-122, Evanston, IL 60201 ($0.45 postage and a self-addressed envelope).

"Development of a Bereaved Parents Group," by Davidson, Harriet. In: *Self-Help Groups for Coping with Crisis* (Lieberman, M.A. et al., eds.). Jossey-Bass, 1979, pp. 80-94.

"Self-Help Groups in Western Society: History and Prospects," by Katz, A., and Bender, E., *Journal of Applied Behavioral Science* 12:3, 265-282, 1976 (special issue on self-help groups).

"Selected Highlights of Research on Effectiveness of Self-Help Groups," by Medvene, L. Unpublished paper, 1987,

revised. Available from the California Self-Help Center, 2349 Franz Hall, University of California Los Angeles, 405 Hilgard Avenue, Los Angeles, CA 90024.

"Sharing Caring," excerpts from a communications kit developed by the American Hospital Association to assist hospitals in their involvement with self-help groups, 187. Ordering information: Division of Ambulatory Care and Health Promotion, American Hospital Association, 840 Lake Shore Drive, Chicago, IL 60611.

A Survey of Self-Help Clearinghouses in North America, Wollert, R. Unpublished paper, 1987. Write to Richard Wollert, Department of Psychology, University of Saskatchewan, Saskatoon, Saskatchewan S7N OWO, Canada.

Self-Help Groups: The Next Fifteen Years, Goodman, G. and Jacobs, M. Unpublished paper, 1987. Single copies of the original paper available from the California Self-Help Center, 2349 Franz Hall, University of California Los Angeles, 405 Hilgard Avenue, Los Angeles, CA 90024. A revised version titled "Psychology and Self-Help Groups: Predictions on a Partnership" is in press (*American Psychologist*).

Achieving Health for All—A Framework for Health Promotion. Report published by the Canadian Ministry of National Health and Welfare, 1986.

APPENDIX B

SUGGESTED STRATEGIES FOR IMPLEMENTING

THE WORKSHOP RECOMMENDATIONS

Development of Implementation Strategies

After the 16 most favored recommendations were selected by the workshop, a set of possible strategies for implementing them were developed in small working groups. The goal was to consider steps and tasks that might be appropriate and useful in achieving the aims of each of the recommendations. It is important to note that there was not time for the either the implementation work groups or the workshop as a whole to develop consensus on specific strategies. Indeed, many suggested strategies that emerged in the discussions evoked disagreement among workshop participants. It was further recognized that the Surgeon General may not have specific authority to take certain actions. Thus the implementation strategies presented below cannot be regarded as prescriptions, but only as suggestions and ideas that came out of group discussions at the workshop. Finally, many of the suggested strategies were not directed to the Surgeon General but to the self-help movement itself.

Recommendation No. 1: *Develop, fund, and support a proactive national centralized information center for referral to existing self-help groups and clearinghouses and for assistance in the formation of new groups.*

It was suggested that a planning group for this center be appointed and that it include substantial representation by self-helpers from a broad-based constituency. The planning group would assist in evaluating needs and resources in the self-help area and in developing and implementing a plan for a national self-help information center.

Recommendation No. 2: *Increase the effectiveness of self-help groups by facilitating communication among groups and disseminating successful models for self-help.*

Throughout the workshop there was strong sentiment for developing communication channels among self-help groups as well as developing educational materials on self-help for professionals. A suggestion that came out of one of the strategy groups was a national symposium or a series of regional symposiums on the development of partnerships between self-helpers and professionals. In addition to self-helpers and health professionals, participants would include corporations and health care organizations.

Another suggestion was to encourage the publication of articles on self-help in health professions journals, especially articles written by self-helpers and by professionals involved in self-help activities. Workshops and symposiums for sharing of information among self-help groups, as well as establishment of a self-help journal, were also suggested as ways to facilitate communication among self-helpers.

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Several workshop participants emphasized the importance of identifying successful models for self-help and disseminating knowledge of those models to others in the self-help movement. It was suggested that systematic studies, perhaps on a national level, could clarify the processes that determine either success or failure in local self-help groups and national self-help organizations.

Recommendation No. 3: *Incorporate self-help concepts into the policy and practice of governmental and nongovernmental organizations, including health care providers.*

Among the suggestions for implementing this recommendation were (1) a Surgeon General's position paper defining self-help and describing its benefits to public health; (2) encouraging conferences among relevant Federal agencies to consider ways of enhancing the partnership between the self-help movement and the health care delivery system; (3) preparing publications on barriers and facilitators to partnership between self-helpers and health care provider partnership, for dissemination to organizations providing formal health care; (4) giving public recognition to exemplary models of partnership between self-help groups and formal health organizations; (5) increasing awareness about and support for the self-help/public health partnership among selected officials; and (6) including self-help component in appropriate requests for proposals.

Other suggestions included encouraging major associations of health care providers to develop policies to encourage partnership between self-help and public health. It was suggested that the Surgeon General could help in this effort by contacting associations of health care providers, professional schools, foundations, and corporations, as well as elected

officials and State health departments. It was recognized that the Surgeon General would need the support of health professionals, self-help groups, and self-help clearinghouses in such efforts.

Finally, it was suggested that partnership between self-help and public health be included in the formulation of national health goals for the year 2000.

Recommendation No. 4: *Establish a structure within the Public Health Service for the promotion and development of self-help.*

Suggestions for implementing this recommendation included creation of a Federal office, perhaps in the Surgeon General's office, for coordination of self-help activities, with the coordinator chosen with substantial input from self-helpers. Another suggestion was creation of a Federal self-help coordinating committee comprised of representatives from appropriate Public Health Service agencies, with each agency also having its own component for promotion of self-help.

There was also a suggestion that separate self-help coordinating committees be established in the regional offices of the Public Health Service, with nominations for membership to regional committees generated by regional staff and local self-help groups and clearinghouses.

Other suggestions included providing space and support for self-help groups in federally funded buildings, funding of training and research grants in self-help, inclusion of information on self-help groups and clearinghouses in Federal publications pertaining to health, and participation of self-help representatives in future Surgeon General's conferences.

Recommendation No. 5: *Develop multimedia campaigns aimed at the public, human services professionals, and self-helpers.*

There was a suggestion that a mass media campaign on self-help be initiated, focused broadly on self-help rather than on specific problems or groups, and that the campaign be developed in collaboration with an advisory committee of self-help group participants, human services professionals involved with self-help groups, and other interested parties. Among the suggested features of such a campaign were video endorsements of self-help principles and practices by prestigious officeholders such as the President of the United States and the Surgeon General.

Other suggestions included White House sponsorship of an annual awards ceremony to honor outstanding contributors to the field of self-help, production of a multi-authored book about self-help for the general public, development of a speakers bureau, education of media professionals about self-help groups, creation of special telephone directory listings of self-help organizations and clearinghouses, designation of a Day, Week, Month, or Year of Self-Help, and encouraging health maintenance organizations and health insurers to communicate information about self-help services to their members.

There were also suggestions that producers of television shows with a human services theme be encouraged to provide the telephone numbers of self-help groups or clearinghouses that offer services relevant to the theme of the program, that professional health organizations include promotional messages for self-help in their journals, that an audiotape seminar be developed to train self-help groups in public relations skills, and that local libraries collect publications from self-help organizations and maintain reference directories of mutual help groups.

Recommendation No. 6: *Support collaborative research and demonstration projects using methodologies appropriate to self-help group approaches and values.*

There was a suggestion that it might be appropriate to have an organization within the National Institutes of Health, or perhaps in other Federal agencies, to foster and conduct research and demonstration projects on self-help and mutual help. It was felt that review committees for the evaluation of research proposals should include members who understand self-help and mutual help principles. Another suggestion was that conferences be convened involving Federal granting agencies, foundations, other potential funders, self- and mutual help organizations, and individual researchers to develop a research agenda that includes research methodologies appropriate for the study of self-help activities.

Several participants at the workshop recognized that self-help groups themselves need to develop an understanding of the importance of research: what it can do directly for the groups, its usefulness for explaining the self-help philosophy and approach to a wider audience, the ability of involvement in research to influence professionals and develop future support, and the potential of research to provide concrete financial support to groups.

Recommendation No. 7: *Develop mechanisms for linking self-help resources and the formal services delivery system as equal partners, giving special consideration to programs for special populations.*

A suggestion that emerged from discussion was creation of a permanent commission to guide national policy on linkages between self-help groups and formal delivery systems for health and human services. The membership of the national

commission would include members of self-help organizations, professionals in the delivery system, and management personnel.

A suggested mechanism to promote linkages, which some felt might be encouraged by the Surgeon General, was periodic conferences of self-helpers, health professionals, and health system managers. Suggestions included annual regional conferences of representatives of these constituencies in administrative regions of the U.S. Department of Health and Human Services, annual national conferences of these same constituencies, and an international conference to be held every three years.

Another suggestion that emerged from discussion of this recommendation was that the U.S. Department of Health and Human Services establish a toll-free telephone service with TDD voice capability to provide information and referral for individuals seeking self-help information, including consumers, self-help groups, self-help clearinghouses, and professionals. (In his response to the recommendations, Surgeon General Koop said he would endeavor to carry out this suggestion.) It was also suggested that the Department of Health and Human Services provide a focal point for collecting, abstracting, and disseminating self-help research findings and results of demonstration projects, as well as proposals for research in the self-help area.

Suggested incentives for more linkages between self-help groups and the health care delivery system included continuing education credits for professionals at meetings that systematically involve self-helpers in conferences, as well contacts by the Surgeon General with professional organizations to point out the value of linkages between the formal health care delivery system and self-help groups. It

was pointed out, however, that self-helpers themselves should also take the initiative in encouraging linkages between professionals and self-help groups.

Recommendation No. 8: *Develop, promote, and incorporate mechanisms to educate primary and secondary school children about self-help through education and health care delivery.*

This recommendation reflected the workshop's belief that primary and secondary school children need to know about self-help. There was also awareness, however, that a valid self-help program must originate among individuals who share a particular problem or need, and that self-help programs instituted by school authorities as part of a curriculum would contradict the voluntary coming together for mutual assistance that is at the core of the self-help philosophy. It was felt, however, that much can be done to raise awareness about self-help among students, school personnel, and parents.

Several suggested strategies came out of the discussion of this recommendation. One was that the visibility and credibility of self-help at this level could be enhanced by public endorsements by the Surgeon General, the media, celebrities, government agencies, professional organizations, and self-helpers themselves. The aim of such strategies would be to help school personnel and parents understand and appreciate the benefits self-help activities can bring to students from kindergarten through high school. It was recognized, however, that self-help materials directed to children should be sensitive to their diversity. It was felt that materials should emphasize the value of peer support and mutual help, of being good friends and neighbors, and should always be appropriate for the age group being addressed. Suggested avenues for dis-

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seminating self-help materials and information included clearinghouses, youth agencies, United Way organizations, libraries, schools, school speaker bureaus, community charitable organizations, parent advocacy groups, and parents and teachers associations.

There was recognition that marketing strategies need to be developed to emphasize the value of self-help in ways that are understandable to school boards, principals, teachers, students, school nurses, vocational and disability counselors. It was also recognized that these efforts would need to be continuous and would require the participation of self-help groups and regional and national self-help clearinghouses.

Recommendation No. 9: *Establish, coordinate, and strengthen self-help clearinghouses and other networking resources at national, State, and local levels, with self-helpers having equal involvement in governance and implementation.*

Many workshop participants saw a need to strengthen self-help clearinghouses and other networking resources at national, state, and local levels. They also felt that guidelines were needed to ensure that self-helpers are involved equally in the governance and implementation of self-help clearinghouse activities, including mission statements, organization, evaluation, accountability, responsibility, ethics, and standards.

Other suggestions included the drafting of a generic grant proposal to guide self-help organizations lacking proposal-writing experience in seeking funds from national, State, and local grant sources, a task that some felt would be appropriate for International Network of Mutual Help Centers.

It was also suggested that appropriations from Congress be sought to provide matching funds to States for the establishment and perhaps the maintenance of self-help clearinghouses, and that a task force of self-helpers and organizations such as the American Hospital Association be formed to develop financial resources for strengthening self-help networks.

Recommendation No. 10: *Establish a national center or institute to fund, coordinate, and facilitate research, training, and dissemination of information on self-help.*

There was support for the idea of creating a nonprofit organization to develop and implement ideas that emerged from the workshop discussions. There was a suggestion, for example, that the Workshop planning committee appoint a steering committee to explore the feasibility of a national self-help center to continue what had been initiated at the workshop. The center, which might be housed either alone or in a university setting, would have majority representation by persons from self-help organizations. One of its early responsibilities would raising seed funds to further its future development into an organization that could further the broad aims of the self-help movement. A further responsibility would be coordinating information from existing clearinghouses and promoting the expansion of the self-help clearinghouse system to all States, not competing with existing clearinghouses.

Other suggested functions for the national center included: (1) identifying public and private funding sources for self-help groups across the Nation, promoting self-help through survey mechanisms; (2) identifying models of collaboration between self-help groups and public and private agencies and disseminating information of the factors that

account for their success; (3) developing pilot projects to demonstrate the need and effectiveness of self-help groups; (4) developing policy on issues that affect self-help groups; (5) as capability develops, serving as a funding conduit for basic and applied research on self-help issues that affect all self-help groups; (6) developing networks among self-help groups with similar interests across the Nation; (7) developing training programs for professionals and self-helpers; and (8) urging the inclusion of self-help components in research proposals solicited by Federal and private granting agencies.

Recommendation No. 11: *Channel resources for self-help into underserved areas and populations such as minorities, rural areas, low-income people, the aged, people with disabilities, alternative family groupings, the homeless, and youth.*

Some workshop participants were concerned that existing definitions of underserved areas and populations may be excluding some who need help, and it was suggested that existing Federal definitions of minority and underserved populations be reviewed to identify underserved areas and populations not included in existing definitions. There was sentiment favoring a study to determine the existence of such excluded groups and identify any self-help mechanisms they may have developed. It was also suggested that culturally sensitive self-help components be developed in programs for all underserved populations.

Recommendation No. 12: *Develop and advocate national policies that recognize the validity and role of self-help groups in the full age spectrum of American society.*

Workshop participants strongly felt that self-help should be a public health matter of high priority and that the validity of self-help and mutual help should be

reflected in public policy. There was insistence, however, that the autonomy of self-help groups, which is one of their core features and essential to their success, be respected. Many participants felt that public policy should focus on goals related to the development of a barrier-free society, and that self-help is crucial for achieving that end. A continuing focus within the Office of the Surgeon General on the roles of self-help in public health was considered essential by most participants. They also felt that participation by representatives of self-help organizations in shaping public health policies and objectives is essential.

There was a suggestion that an Office for Self-Help be established in the Department of Health and Human Services to provide liaison with self-help organizations and public health programs, sponsor self-help meetings and conferences, influence funding for research programs, and coordinate access and linkage between self-help groups and public health programs.

It was also suggested that ad hoc interdepartmental and interagency task forces with self-help group representation be established to influence policy, funding, programming, and program evaluation in such health issues as "orphan" diseases, low-incidence diseases, problems of the aged and the homeless, financing, insurance, and third-party reimbursements.

Recommendation No. 13: *Increase minority leadership in the self-help movement and enhance the sensitivity of self-help organizers and groups to culturally diverse populations.*

Workshop participants recognized that self-help groups are not always sufficiently sensitive to the special needs of minority groups and that minorities need greater representation in the leadership of

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the self-help movement. It was also felt that many existing Federal programs could be enhanced by the inclusion of minority group leaders from self-help organizations, and that the influence of the Surgeon General might be helpful in achieving this goal.

Suggestions to implement recommendation 13 included holding a national conference to deal with minority self-help issues and enhance the relationships of minorities with human services agencies, self-help organizations, and other voluntary associations. A number of resources in both the public and private sectors were suggested as potential underwriters of such a conference. Other suggestions included establishment of incentives, such as a national fellowship program for minority leaders and a minority technical assistance networks, to promote the concept of self-help within minority communities and identify leaders within those communities.

Development of outreach and education programs on self-help for minorities at the community level was also suggested. It was emphasized that bodies established to carry out these programs should include representatives of the target communities and reflect the composition of those communities.

Recommendation No. 14: *Incorporate information and experiential knowledge about self-help in the training and practices of professionals.*

Workshop participants generally considered this recommendation as one of the most crucial for developing effective partnerships between self-help and mutual help groups and the formal health care delivery system. Many participants felt that the influence of the Surgeon General could be very helpful in increasing awareness of self-help principles in the health

and human services professions, including students preparing for careers in those professions. There was considerable agreement that such training would be greatly enhanced by involving self-helpers who could share experiential knowledge of self-help in relation to their own particular health problems.

It also was felt that people already in the health professions need to know more about the potential of self-help groups to benefit their patients, and again it was suggested that encouragement by the Surgeon General could be helpful in bringing about the needed changes.

Recommendation No. 15: *Develop and influence public policy through networking, coalition-building, and advocacy.*

There was sentiment favoring a study of self-help clearinghouses to understand their activities and to publicize those that may benefit self help groups and their members. Participants felt that such studies could increase the ability of clearinghouses to strengthen self-help groups' ability to organize, develop referral and recruitment systems, form networks, develop advocacy programs, and build coalitions. Such studies were also perceived a helpful for developing better patterns for representation of self-help groups in the operation of these agencies. It was also suggested that international and regional meetings of self-help group leaders and activists be conducted to develop links and networks among groups with similar constituencies, conditions. Some participants also felt that the Surgeon General could be instrumental in arranging meetings of self-help group leaders and national organizations of professionals and human service providers.

Another suggestion was development and funding of an Independent National

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Council on Self-Help modeled after the National Center on the Handicapped. This effort, for which Federal funds might be solicited, would involve the efforts of self-help advocates and national self-help groups. Here, too, participants suggested that the Surgeon General's office could play a helpful role.

There were also suggestions favoring ongoing training in advocacy skills for self-help groups, including distribution of information on advocacy skills through newsletters of self-help groups and clearinghouses and convening of local conferences for advocacy training for self-helpers in cooperation with clearinghouses and self-help groups.

A White House Conference on Self-Help was suggested as a fitting way to inaugurate an International Year of Self-Help and creation of a National Council on Self-Help.

Some participants urged doing away with the prohibition of advocacy by some nonprofit organizations, saying that self-help groups and other nonprofit organizations should be allowed to influence public policy.

Other suggestions favored the development of public and private sector alliances in self-help group operations and funding; formation of links between self-help groups and other citizen organizations around specific issues; development of a national newsletter for self-help groups; development of ongoing coalitions among local, State, regional, and national self-help groups; and dissemination of the workshop's recommendations by the Surgeon General, with encouragement of their implementation.

Recommendation No. 16: *Increase Federal, State, local, and private funding for self-help groups and activities.*

Since funding is a chronic problem for many self-help organizations, several suggestions on how to alleviate it emerged from workshop discussions. One was to train self-help leaders in grantsmanship in order to increase the chances of funding for self-help groups. Another was for appropriate Federal agencies to establish self-help as a generic field for priority funding in order to counter a perceived tendency of current funding sources to favor funding of projects related to specific conditions.

There was also a suggestion that administrative procedures for contracts, requests for proposals, and grants by made compatible with self-help principles to permit compliance by self-help groups. Another suggestion was drafting model legislation to support and enhance self-help as part of the health services delivery system. Participants felt that this was mainly the responsibility of self-help groups, but that help from entities experienced in drafting such legislation would be needed.

Other suggestions included training and technical assistance programs for self-help groups in economic development and self-sufficiency; initiation of a corporate campaign to include self-help in health promotion and disease prevention efforts; modification of third-party payment policies to allow reimbursement for participation in self-help activities; assistance of the Surgeon General in encouraging dissemination of information on potential grant funding sources to self-help organizations; inclusion of self-help linkages in existing and new health delivery and prevention programs; and documentation of the current funding levels for self-help groups by Federal and State governments and private foundations, to facilitate prudent financial planning by self-help organizations.

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ON SELF-HELP AND PUBLIC HEALTH

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